mnda
motor neurone disease
association

Response to Department for Work and Pensions consultation on Personal Independence Payment: aids and appliances descriptors

Introduction

i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.

iii. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

iv. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65.

v. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

vi. This consultation, rather than seeking to correct a failure in meeting the original policy intent of Personal Independence Payment (PIP), marks a strong attempt to move away from that intent. Its conjecture is that aids and appliances are often low-cost and one-off purchases, or may be items that are already available to the person that needs them. In the context of the PIP assessment, this is wholly irrelevant; the system does not work on the basis of a calculation of real extra costs. Instead, descriptors act as proxies for extra costs. Costs such as extra heating, higher water bills, new clothes and insurance, among many others, are not assessed and calculated. If the DWP is interested in reforming the PIP assessment system so that it does capture the full range of extra costs that people with MND and other health conditions face, then we are happy to explore that option. In the meantime, it is unacceptable to initiate a process that would restrict eligibility on the basis of an assumption about the cost of aids and appliances, without due regard to not only the full range of aids and appliances that people with MND use, some of which are very expensive, but also the full range of extra costs associated with their condition.

vii. Aside from this overarching flaw in the policy basis of this consultation, the evidence on which it is based is also extremely problematic. To pursue major policy change which would see 35% of claimants deemed ineligible for PIP, including around 10% of people with MND who apply through normal rules, despite the severity and progressive nature of the condition, on the basis of a 0.02% sample of claimants is irresponsible at best. There is no robust conclusion about the operation of the benefit that can be drawn from such a small sample.

viii. On this basis, and for the reasons expanded upon below, we are unable to support any of the proposed alternatives. While we would welcome the opportunity to engage with the DWP on how the benefit assessment process can be improved, including how it can better take into account progressive conditions such as MND, we do not accept that this is one of the problems that needs addressing, or that these options will do anything other than harm people with disabilities, including people with MND. The DWP must halt this process, and ensure that people with complex disabilities and health conditions are not denied the financial support they need.

1. General comments on the consultation

i. Overall, we are concerned that this consultation has been presented in the manner that it has. We believe that the premise of this consultation is wrong, as are the conclusions that it draws. It is based on a sample of 105 people who have been awarded PIP. This represents just 0.02% of all current claimants, according to the Department for Work and Pensions (DWP),[1] and yet general conclusions about the eligibility of a significant number of claimants have been drawn. This includes approximately 10% of people with MND who have claimed PIP under normal rules since the beginning of the benefit, based on information provided by the DWP.[2] To base such serious policy proposals, which would take away financial support from over a third of total claimants and one in ten future claimants with MND, a progressive and terminal illness, on such a sample is both irresponsible and methodologically unsound.

ii. Furthermore, we do not agree that there is a demonstrable failure in the original policy intent of PIP simply because 35% of claimants qualify for PIP on the basis of assessment against ‘aids and appliances’ descriptors. Rather, we maintain that this is a legitimate means of demonstrating need and qualifying for the benefit. People who are assessed as needing aids and appliances across a large range of daily activities, including activities as diverse as washing, eating, managing toilet needs and communicating verbally, have significant and complex needs, and will face significant extra costs as a result. The PIP assessment system is not designed to quantify each individual cost, but to provide an indicator or proxy of

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[1] Personal Independence Payment: written question 20826 http://bit.ly/1VdYiWm

[2] Personal Independence Payment: Motor Neurone Disease: Written question – 23387 http://bit.ly/1RL2Ohc

the level of support a person is likely to need. There is no evidence presented in this consultation that indicates that this system is not working.

iii. The consultation implies that a significant percentage of people who receive PIP should not be entitled to it, and thus the eligibility criteria needs to be tighter. The Department has stated that this is also the conclusion of the first independent review of the PIP assessment by Paul Gray. However, Gray in fact concluded that it would be necessary to make adjustments to the guidance and training provided for Health Care Professionals (HCPs) conducting the assessments to ensure they were assessing the need for aids and appliances correctly. He did not recommend that the assessment criteria should change.[3] Based on the information provided by the DWP in this consultation, there is no evidence that people who should not be receiving PIP are receiving it.

iv. In addition, we have serious concerns about the implications of all of the proposals for passported benefits such as Carer's Allowance, which many carers of people with MND rely on. Furthermore, we believe that any option that brings disabled people into the scope of the benefit cap is contrary to the Conservative Party's 2015 Election Manifesto pledge to protect people with disabilities from the impact of this policy.[4]

v. We feel that the DWP has launched this consultation at an inopportune time. Not only has the consultation period fallen over the winter break, restricting the available time to research and formulate a response, but it has come at a time of considerable additional reform to the benefit system. Most pertinently, claimants are still being assessed for eligibility to move from Disability Living Allowance (DLA) to PIP; to change the nature of the benefit and the benefit assessment at this critical time carries a significant amount of risk to both a system still under the pressure of waiting times and quality issues, and to the claimants who are subject to the impact of the reforms.

vi. However, we welcome the approach that the DWP has taken in ensuring that organisations such as the MND Association, as well as people with MND and other conditions, are able to feed into this consultation at events around the country. We hope that this open engagement continues, and we will write separately regarding improvements and extra support that could help these events in the future.

2. Question one: views on the current system and its advantages and disadvantages compared to the options proposed

i. We believe that, on the basis that no compelling evidence has been presented that there is a need to restrict eligibility, and given the high number of current and future claimants with complex needs that would be negatively affected by the proposals, the current system must be retained.

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[33] Paul Gray, *An Independent Review of the Personal Independence Payment Assessment* (December 2014), http://bit.ly/1r03SSh

[4] Conservative Party Manifesto (2015), http://bit.ly/1FPYN2z

ii. As the consultation document itself notes, the activities used by the PIP assessment are designed to be proxies for, or indicators of, the extra costs associated with disability; descriptors '[reflect] the ease or difficulty with which a person can carry out the task as a proxy for additional costs'.[5] For this reason, they are not exhaustive. Costs for people with MND that are not covered by the assessment include extra heating, electricity, new clothing as the person's body changes, different foods and more. It is worth noting that the pan-disability Extra Costs Commission found that the average PIP award fell short of the average extra disability-related expenditure by almost £200 per month.[6] If the Government chooses to pursue a model that does itemise and compensate for real costs, it may find itself spending considerably more than at present, and taking considerably longer to process applications. If the DWP is interested in exploring this option, however, we would welcome the opportunity contribute evidence from people with MND, and how the system could better support them to meet these costs.

iii. As stated, these descriptors are designed to capture the cumulative impact of disability, and if a person needs to use an aid or appliance to dress themselves, eat, manage toilet needs and speak or hear, that implies a considerable cumulative impact and a high level of need across a diverse range of daily living activities. Each of the proposals put forward by the DWP ignores these facts and these extra costs. Instead they focus on specific, individual item costs, assuming that this represents total cost. This is despite the fact that the DWP itself, when designing the PIP system, rejected a system based on itemised, actual costs on the basis that this would be 'subjective, inconsistent and expensive to administer'.[7]

iv. The current PIP assessment provides only a snapshot of particular needs at the time when it is carried out; people with progressive conditions such as MND will face mounting extra costs as their disease gets worse. Any options to either limit the amount or regularity of payments would thus put families living with MND in a difficult position as they try to plan for and meet these costs. Mrs A, an unpaid full-time carer for her husband who is living with a rare form of motor neurone disorder, Kennedy's Disease, said the following on this subject:

> There is no recognition within this document of people getting progressively worse. For example, in Kennedy's disease, whilst deterioration may be slower, it is never ending and you will only continue to deteriorate over time; meaning that aids and adaptations made now will not be sufficient into the future... You can notify of changes and this process of re applying at the rate someone with MND/Kennedy's disease needs is costly and time consuming.

v. The assumptions in the consultation document that aids and appliances are all low-cost, one-off purchases is also flawed. Some may be low-cost, but for

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[5] DWP, Consultation on aids and appliances and the daily living component of Personal Independence Payment (2015), http://bit.ly/1NZP29m

[6] Extra Costs Commission, *Driving down the costs that disabled people face* (2015), http://bit.ly/1PaNKY3

[7] DWP, *Personal Independence Payment: second draft of the assessment criteria* (2011), http://bit.ly/1S9CKuV

someone with a progressive disease like MND these costs may need to be met often as needs change. Likewise, many aids and appliances for people with MND are not low cost at all:

> Whilst they may seem to be small expenses in themselves; some things are not. For example, due to transfer difficulties we will need a different sofa/ chair for [Mr A] to sit in.

vi. Even where the item is low-cost or ‘everyday’, it is important to remember that the PIP assessment is not designed to determine that particular cost; the descriptors are meant to be a proxy for a level of need. Indeed the cost of an aid or appliance has already been acknowledged by the DWP as irrelevant. The PIP Assessment Guide states that *‘*It is reasonable to expect a claimant to use an aid or appliance […] available at no or low cost’*.* [8] The cost or type of aid or appliance is not the focus; it is how and why the person needs it and what that tells an assessor about the impact that their disability or health condition has on their life.

vii. It must be remembered that a key part of the assessment is whether a person can complete tasks safely, reliably, repeatedly and in a timely manner. This consultation does not make reference to the importance of these factors in conducting an assessment at all. Mrs A raises this point as well:

> There is nothing about whether the person is actually safe whilst undertaking the activity. For example, balance is severely affected with muscle wastage and loss and whilst you could sit on a stool in front of the oven to take something out; your actual balance is such that you cannot hold your posture to make the movement safe. The aid or adaptation is half the story. The other half is whether the person should do it from a risk point of view. To pick up a cup for example at the moment [Mr S] will have to put one crutch down, leaving him unbalanced. The cup would be only half full as he shakes so much when concentrating enough to pick something up. We have bought plastic glasses, plates and cups as it is safer if they are dropped but just having the plastic cup is not enough. Whilst a plastic cup is a small expense, the real expense is me, at home, ensuring he has a drink that he doesn’t spill on himself and remains safe.

Mrs A is able to help her husband because she is in receipt of Carer’s Allowance. Her husband’s award acts as the passport to this benefit. All of the proposed options would mean that carers like Mrs A would lose this vital financial support, either because the nature of the new benefit would not act as a passport, or because the person they care for no longer qualifies for PIP.

viii. We believe that one likely impact of pursuing any of these proposals is extra pressure on health and social care services. Each proposal would restrict eligibility for crucial financial support. The needs of people with MND and the needs of their carers will not go away if the benefits that they claim are reduced. They will, however, face mounting extra costs without the means to meet them. The risk that their needs will increase at a faster rate, and that they will be at greater risk of

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[8] DWP, *PIP Assessment Guide* (2015), http://bit.ly/1DmDdVM

injury and ill-health, putting more pressure on an already struggling care system, is very real. Any changes to PIP eligibility need to carefully consider knock-on effects on other parts of the system. Otherwise, cost-savings to Government will not be realised.

ix. For these reasons, as well as problems already highlighted with the nature of this consultation, we believe that it is important to preserve the current assessment system, rather than pursuing any of the options outlined by the consultation paper. There are a number of additional problems with the options themselves, which are detailed below.

3. Question two: views on the advantages and disadvantages of option one compared to the current system and other options proposed

i. For the reasons outlined above, we do not believe that option one has any advantages over the current system.

ii. In addition, we believe that this option would be extremely difficult to achieve, particularly if the voucher system were pursued. It would potentially require significant investment in occupational therapy services in order to determine what equipment is needed for a person, approved supplier partnerships would need to be developed to make it possible to spend the vouchers, and it could open up questions of liability for the DWP regarding malfunctioning or inappropriate equipment if proper protections were not in place.

iii. In addition, aids and appliances such as specialist wheelchairs, riser recliner chairs and others can be extremely expensive, and as a condition such as MND progresses may need changing or replacing a number of times. Given that the voucher or payment would be less than the current standard daily living rate paid, it may not be sufficient to cover these high value items and regular repeat costs. This proposal also fails to account for the full range of extra costs that a person faces as a result of their disability or health condition; if a person has multiple, complex needs across a range of daily living activities, their costs will be in excess of those recorded by the PIP assessment.

iv. We are very concerned at the potential that this proposal has to exclude people with a very high level of support needs across every aspect of daily living, simply because they are only scored against aids and appliances descriptors. It is conceivable, within the context of the proposal as currently written, that a person might score highly as a result of needing aids and appliances to allow them to prepare food, eat, manage their health condition, wash, manage toilet needs, communicate verbally and read and understand written material, but who would only qualify for a lower-value lump sum or voucher, while another person who scores fewer points across fewer daily living activities, but scores one against a ‘c’ descriptor, carrying the same points value, qualifies for the benefit. It is not our contention that either person is more or less in need of financial support, precisely because this assessment is only a proxy for their support needs and extra costs; it is that their disability affects their respective lives in different ways, and is recorded by the assessor in different ways, but that both are in need of support. It is thus both unfair and incorrect that that one person would qualify for the full benefit and the other for only a voucher.

v. Finally, we cannot endorse any proposal that would deny carers for people with MND access to Carer's Allowance. Carers UK and the University of Leeds estimate that unpaid carers save statutory services £132 billion a year.[9] Over half of carers for people with MND provide over 100 hours of care per week, and rely on this benefit as an income replacement. Depriving carers of financial support risks their wellbeing and their ability to provide care. This in turn would place additional burdens on health and care services, on top of the extra potential burdens discussed above as a result of people being moved off PIP itself.

4. Question three: views on the advantages and disadvantages of option two compared to the current system and other options proposed

i. For the reasons outlined above, we do not believe that option two has any advantages over the current system.

ii. Again, we are very concerned at the two-tier system of eligibility that this proposal would create, where people with broadly equivalent support needs would qualify for very different levels of support. Again, this assessment is only a proxy for their support needs and extra costs; the same disability will affect different people's lives in different ways, will be managed in different ways by that individual and is recorded by the assessor in different ways. Both are in need of support, and should be treated equally by the assessment system.

iii. The current PIP assessment system does not measure costs such as clothing, heating, transport or insurance, and does not take into account how needs might progress. In the case of someone with MND, these needs may progress extremely quickly.

iv. As stated previously, we cannot endorse any proposal that would deny a carer access to Carer's Allowance. Similarly, we cannot endorse any proposal that would recognise a person's disability, and yet still bring them and their household within the scope of the benefit cap. As argued above, this contradicts the Conservative Party's manifesto commitment to protect this group from the cap, and fails to recognise the range of extra costs that someone with a disability or health condition will face. Restricting their income in this way will only compound the financial difficulties that they already face.

5. Question four: views on the advantages and disadvantages of option three compared to the current system and other options proposed

i. For the reasons outlined above, we do not believe that option three has any advantages over the current system. As previously discussed, this would create a two-tier system of entitlement which we believe would be unfair.

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[9] University of Leeds, *Unpaid carers save the UK £132 billion a year – the cost of a second NHS* (2015), http://bit.ly/20xblWw

ii. This proposal would mean that people with valid claims and high levels of need across multiple descriptors would not qualify for PIP, which is clearly wrong. A person might score 15 points, which would normally qualify them for a higher rate PIP award, across the eight different daily activities that ask about aids and appliances, and still not receive any financial support to help them meet their extra costs. The complexity of creating a system that scored descriptors in this way would be immense and we believe would lead to considerable confusion amongst the healthcare professionals (HCPs) responsible for making recommendations to the DWP. We also believe that it would be difficult to explain to claimants why, despite scoring sufficient points to qualify for even the higher rate of PIP, they had been deemed ineligible. Imposing a limit on the number of points that it is possible to score against aids and appliances descriptors ignores, again, the fact that this assessment is designed to capture cumulative need, and is meant to be a proxy for extra costs. Scoring this many points across this many activities is a clear indication of the cumulative impact of their disability; to take away their support goes against the intention of the benefit.

iii. For those who do not score against another descriptor, and thus are deemed ineligible despite clearly complex needs, this will result in extra pressure on social care services both from those with disabilities and health conditions such as MND, and from the people who care for them, who are no longer passported to Carer's Allowance.

4. Question five: views on the advantages and disadvantages of option four compared to the current system and other options proposed

i. For the reasons outlined above, we do not believe that option four has any advantages over the current system. In addition, we believe that this proposal is simply unworkable, given the complexity of developing a list of 'approved' aids and appliances, and the considerable volume of case law that would result.

ii. Again, the need to use a bed or a chair to be able to stand and dress is an indicator that a person has considerable needs, which must be recognised. It is not the type of aid or appliance that should be examined; it is how and why the person needs to use it and what that tells an HCP about the impact of their disability on their life. The fact that a non-disabled person may use plastic cups and bowls should not be a reason to exclude such items from an assessment that is designed to be a proxy of support needs; in Mr and Mrs A's case, discussed earlier in this response, these are necessary items which clearly describe how an area of Mr A's life is affected by his health condition, with clear implications for other areas as well.

iii. We decline to comment on which classes and types of aids and appliances are a good indicator of extra costs, as we do not believe that this is a valid question for precisely the reason discussed above; needing an aid or appliance is a proxy for extra costs and an indicator of extra need. Whether that item is specialist, expensive or otherwise is irrelevant.

5. Question six: views on the advantages and disadvantages of option five compared to the current system and other options proposed

i. For the reasons outlined above, we do not believe that option five has any advantages over the current system.

ii. This option would mean that a person would have to score against all of the aids and appliances descriptors across all eight activities in which they are featured. If this were the case, only the most severely disabled people would qualify, while others with considerable support needs and extra costs would lose out. This could include people with MND at an early stage of diagnosis, despite the fact that their needs and costs will increase, and in most cases very quickly. Again, aids and appliances descriptors are meant to be used as a proxy for extra costs; to suggest that only people who need prompting to undertake different activities, or only people who need to use an aid or appliance in every single aspect of their life, face these extra costs is nonsensical.

iii. Approximately 10% of successful applications made under normal rules by people with MND were awarded on the basis of scores against only aids and appliances descriptors. To potentially deprive one in ten claimants with MND of their benefit by restricting eligibility in this way, when they are fighting to manage a devastating, progressive and increasingly expensive disease, is unacceptable. To suggest that people with MND need to wait until their condition has progressed to the point where they need a significant level of personal support before their life will be affected or before they will face extra costs is simply wrong. The costs for someone living with MND will mount, and new equipment, aids and appliances will have to be purchased as their condition deteriorates and their needs change.

iv. The PIP assessment already only captures a minority of these costs; creating a system where none of these costs are recognised will mean that people with MND are less able to manage financially. Their needs will not go away, but are likely to get worse at a faster rate without support. Again, the risk that this policy proposal creates for extra pressure on health and social care services is substantial; the DWP must seriously consider the full range of system costs that will arise from such a change and act in a way that does not exacerbate an already challenging situation.

6. Question seven: other suggestions as to how the current system could be changed and any other comments

i. For the reasons stated above, we do not believe that any of these proposals are appropriate alternatives to the current PIP assessment system. We believe that there is room for improvement in the operation of PIP, but we understand that those improvements are beyond the scope of this consultation.

ii. The consultation period itself has been disproportionately short, and has fallen across the holiday period. This has made it extremely challenging to engage meaningfully on these issues. The fact that an invitation to a PIP Implementation Stakeholder Forum working group meeting on the consultation was issued on the 21 December, with a response closing date of the 4 January, for instance, was extremely unhelpful. We hope that in the future the DWP will avoid issuing consultations over this period and will allow stakeholders sufficient time to generate a meaningful response.

7. Conclusions and recommendations

This consultation is based on an extremely limited evidence base, and comes at a time of large scale reform to the PIP system, alongside other elements of the benefits system. The proposals put forward restrict eligibility to PIP, and would result in 35% of total claimants, and one in ten normal rules claimants with MND, losing their benefit. The impact of this would be significant and extremely damaging for those claimants affected, as well as for their carers who would no longer be passported to Carer's Allowance. For all of the reasons outlined in the response above, we urge the DWP to halt this process and to retain the current PIP eligibility system.

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